

**A C T U P
O R A L H I S T O R Y
P R O J E C T**

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Interviewee: **Anna Blume**

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Interviewer: **Sarah Schulman**

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**ACT UP Oral History Project
Interview of Anna Blume
January 25, 2010**

SARAH SCHULMAN: – say your name, your age, today’s date, and where we are.

ANNA BLUME: All right. My name is Anna Blume. I’m 51 years old. And we are in Brooklyn, New York, Clinton Hill.

SS: And you look very handsome today, Anna –

AB: Thank you.

SS: – have to say. So, let’s start at the beginning. Where were you born?

AB: I was born in Los Angeles, California, in 1958.

SS: And what did your parents do? Were they American?

AB: They were second-generation Americans. My mother’s family came from Germany; my father’s family came from Austria.

SS: So they were second-generation Americans. So your grandparents were born in America?

AB: They were. They came quite early, though. When they were younger, before the wars, they were Jews. And they came before – in some cases, before the First World War. Because there was already such difficulty for Jews in Europe at the end of the 19th century.

SS: I see. And how did they end up in Los Angeles?

AB: That – that has to do with scandal and difficulty. Both my parents’ families settled in the East Coast; my mother’s family in New Haven,

Connecticut, and my father in Brooklyn. And my mother's mother was an opera singer, and eloped with a French gigolo, and ended up in Los Angeles, and that's where my mother was born. And then my father's father was a bit of a gambler, and lost everything, and tried to start over again in Los Angeles, and that's how my dad ended up on the West Coast.

SS: So did they work in the entertainment industry at all, or did they avoid that?

AB: No. They both were part of families that were trying to get new starts, and the West was still wild, and –

SS: So what were their jobs, when you were a kid?

AB: My father's family was in the garment business, and he was a trucker. And my mother was a fashion coordinator for my uncle, my father's brother. And that's how they met. My father – I'm not sure he graduated high school. But he was ambitious, and my mother was even more ambitious. And they actually got involved in general contracting and building. Which was a very lucrative world for them, in the '50s and '60s, '70s and '80s, in Los Angeles. So they did very well.

SS: So when you were growing up, what kinds of messages did you get from your parents about community, social responsibility, politics?

AB: To a certain extent, kind of mixed messages. I think that my mother was always a staunch Democrat, and she was a Kennedy girl and,

Kennedy woman, and spoke about really liberal ideas, and encouraged us to be conscious. On the other hand, I think we were just a fairly typical bourgeois, self-insulated family. And so there was a lot of talk, and not a lot of doing.

SS: I'm sure that you — because we're the same age, and you probably grew up seeing things on the news about Vietnam, about riots — was there any kind of commentary in your home about those things?

AB: Vietnam was pretty invisible, strangely enough. But the deaths of the Kennedys, and Martin Luther King, was not invisible. And in fact, I think that impacted my mother tremendously, and I think shaped me, and still shapes me, to this day. The thought that we live in a country where people that may say things that I might agree with are very dangerous and vulnerable — dangerous, that is, in the perception of others. And so that I think fairly early on, I was encouraged to think socially, but I also was shown historically that one would be very vulnerable if one took that path, at least in this country. Within my household and in the general world, these were the messages I was getting. One might want a better world, but there will be forces that you'll have to contend to if you want to think about that, and do something about it.

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SS: So when you were in high school, which came first for you; queer, art, or politics?

AB: {LAUGHS} Well, queer and art to me are kind of the same things, so I would say they were equal.

SS: How did you get that message, that they were equal?

AB: Well, I think that my queerness was there as far back as I can remember. And I also understood it as something deep and hidden, and that you needed to be creative if you were going to live that life. And so it was always about storytelling, to myself and to others. So I think the kind of creative imagination and queerness were just completely fused to one another. Politics came later.

SS: Did you have a community in high school, about queer and art; like the arty kids? Or was it kind of an isolating –

AB: Well, I was in high school during the '70s. And queerness, I'm not sure, was even a word yet. And I was in Los Angeles, so boy queerness, like homosexuality, or fags, were all over the place — my mother's hairdressers, the decorators — and that was talked about, and it was a fairly integrated part of our world. But female homosexuality, or — that was totally invisible. And as I became more and more sexually experimental — especially in how I looked and my appearance — my mother was just completely appalled, and terrified, actually.

But I went to an all-girls private school. And I felt like intuitively, people knew I was queer, and they were very supportive. But it wasn't anything overt, or — open.

SS: So did you already know that you were interested in art history at that point? Or was that something that happened later?

AB: I guess that for me, my sexuality and my interest in aesthetics are, they're so – integrally part of me, I can't really separate myself from them. There's no one moment where they became important, or stopped becoming important.

SS: Where did you go to college?

AB: I wanted to go as far away as possible.

SS: Right.

AB: So I only applied to one school — early decision — which was Williams College, in the mountains, the Berkshire mountains, of Massachusetts. And my parents didn't even quite know where that was, or what that was. And when I got in, I said, I've signed a contract, I have to go. And so they agreed, and that's where I went.

SS: So when you got there, did a lot of these things start to articulate for you?

AB: Well, it was a huge transition. I knew I wanted to go, and I was so anxious to go; even told my parents that school started in July, and I went a month early, heh, and had to get a job to support myself. And actually they don't know that. {LAUGHTER} Never really told them that. But anyways, that was many years ago.

It was shocking to be on my own. It was also shocking to be on the East Coast. It was really cold here. And I knew a great deal about myself, internally; but I hadn't really lived that life along other people. And at Williams in '77, '78, issues around gays and lesbians just began to become spoken about. And I joined the gay and lesbian organization, like the third week of school; and felt it was just a very powerful period. But it was long and hard.

SS: Was that separate from a feminist organization on campus? Were those two different things?

AB: They were completely different. I don't really even know that there was a feminist organization yet at a place like Williams. But there was a gay and lesbian organization; and it was new.

SS: And what were some of the things that they were concerned about?

AB: Well, I got involved very early on with the campaign to include sexual orientation as something in the nondiscrimination clauses. And this led to huge debates in the faculty, as to what that would actually mean. And I remember Eva Grudin, who was this great German faculty member. And we snuck in; a group of us snuck in to the faculty meeting, and listened to it, and tape-recorded it. And I remember Eva Gruden saying to the president of Williams at the time: was he worried that undergraduates would be fucking camels on the library steps. It wasn't, this wasn't about bestiality. And we blew our cover,

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because we started laughing so hard, and they had to stop the meeting, and usher us out. And so that was, I remember, a major issue for us.

SS: Did you win?

AB: Eventually, yes.

SS: Oh, okay.

AB: It took a couple of years. I would say the most politically active thing I did in college was just to be out, and to talk about it, and to be known on campus as queer. And I think that, in and of itself, in the '70s, was pretty much a big deal.

SS: What was lesbian life like there? Were there any out professors?

AB: There were some closeted professors that were willing to come to our meetings. And I don't know how closeted they were in their day-to-life, but they certainly weren't out on campus. It was really much more the students that were out. And more men than women.

I remember having people say things to me like, you don't belong here; or conversely, how brave of you to be here, to be what you are. So I felt a little bit like I had an identity on campus, and people knew me; in part, because of my academic work, but also partially because I was an out queer woman on campus.

SS: And so as you start to develop as an intellectual and a scholar; were you frustrated by the positionality of gay work and women's work in the canon of your discipline?

AB: I think at college I was such an aesthete that I just was happy to do the work I was doing, and was completely absorbed in the moment. And in being in an undergraduate, liberal arts college. It was a lot of work, and I felt like just my personal life was so political that I didn't really think any bigger than that. So it wasn't much of a conflict till I got older, really, and the world got bigger for me. But in that little world, of a New England, little Ivy League college; I felt like I was busy all the time, doing what I cared about. There were hazards of being one of the only known lesbians on campus. You'd get midnight arrivals, of women thinking they'd like to experiment. These were experiences I had to get better at.

SS: And did any of them ultimately come out, or was it –

AB: Oh yes, absolutely.

SS: Oh, good.

AB: Some of them were really genuine in their desire to experiment, and some of them – I don't know; it might have truly just been an experiment.

SS: So where did you go from there?

AB: I think by the time I got to my senior year in college, I just couldn't imagine being part of the world, other than staying in school. It was the only thing I ever knew, and the only thing I ever felt comfortable with. So I decided to go to graduate school. And I wasn't even sure what that meant. I never knew anyone who went to graduate school, except, of course, my professors. But I didn't really know what it meant to get a Ph.D., or how long it would be, or how one affords these things, or – I just, it was almost like a dream. I just decided that's what I wanted to do.

So I applied, and got in, and got a fellowship, and didn't have to worry about money for a while, and so I just went.

SS: And where did you go?

AB: I went to Yale.

SS: Okay, so you arrive at Yale –

AB: In 1982, yes.

SS: Yeah. So these paradigms that we've been discussing; were they different at Yale than they had been at Williams?

AB: Well, Yale is a university, and it's bigger; much bigger. I mean, Williams is a teeny little Ivy League college, that's pretty homogeneous. And Yale is in a complex city, like New Haven, with a complex town-and-gown relationship. It's also a university with a law school, a medical school; graduate students, of which I was one.

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When I first arrived, I think I just continued on the path of my aesthetic life. And then I took a year off, and went to Rome, and learned Italian, and worked on my Latin. It's when I came back, in I think '83, '84, that there was a big strike at Yale; a historic strike, of secretaries and clerical workers; the first strike of its kind in the United States. And it was the first time I was exposed to ideas about class and race in ways I hadn't thought about, and gender; and also about the relationship of the university and the city. And they really turned to us, as graduate students, to help with the strike. Because many of us not only were in positions as liaisons between faculty and undergraduates and administration, but many of us also taught classes. And they wanted a shutdown. And we could really helpfully affect that shutdown.

And I was deeply moved and politicized by that strike. And I helped to organize classes off-campus; I helped to organize protests and activities that helped bring – and became aware of how important the press was, how hugely important the press was, in any kind of political activism, especially when you're taking on an institution as big as Yale, with as much of its own egoism and bravado.

And we got very good as kind of guerilla workers, the graduate students. I remember, as the strike was gaining in support, and the students really were stopping going to classes, and we were holding classes in our apartments and in coffee shops all over the city; we also realized that many of the secretaries

and clerical workers were married to the police department and married to the fire department, and married to the infrastructure of the city. And those infrastructures allowed us to really break the stronghold of Yale that was trying to pay its secretaries much less than even secretaries were making in New Haven; because they said, oh well, Yale is such a great institution, and you should be happy to work here for very little.

And I remember a group of graduate students, along with myself, took over the president's office – Giamatti was his name. And I remember: he took me aside, because he remembered me from his Spencer class. And he said: I just want to give you some advice; that your future career is at stake here. And I remember — and I don't even know where this came from in me — but I just remember turning to him and saying: I give you the same advice. And luckily, we won the strike, and he was fired at the end of the year. {LAUGHTER}

So that had a good – but I would that was absolutely crucial in bringing together my own personal history, and my life; what I was studying; the world I was becoming more aware of; and this belief in agency — agency of underrepresented people — when you work together, what's possible.

SS: So did this start to affect intellectually, how you looked at your discipline?

AB: Oh, it was a disaster. I went from studying 15th-century poetry and painting to taking classes with a very important social Marxist historian,

Carlo Ginzburg, from Italy. And he was studying witch trials at the same time, in 15th-, 16th-century Italy. And so class and race and gender and religion started to become hugely important as elements within visual culture; as what's kept out of visual culture and what gets into visual culture. And I started getting interested in European expansion, which meant the conquests of the Americas. And I eventually left the department I was in, and went into art history — I originally was in the History Department — and decided to commit myself entirely to visual culture, but to colonial culture, and especially European and Latin American colonial relations. And so the next three years of graduate school was a total shift, that I think was very much precipitated by the political world I had become part of.

SS: Now were still really mostly situated in a gay and lesbian context? Or was there now a feminist construction that you saw yourself as part of?

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AB: I have never really been much of a feminist, so that wasn't — I'm not even quite sure I'm a woman, so it's a little hard to — not that you need to be a woman to be —

SS: Right, of course.

AB: — a feminist, of course. But I think that my struggles have been more around class and gender, but in broader ways, I guess. In terms of Yale — like I mentioned, it was a much bigger institution, and had a life within a

city. And so my context was not just my colleagues in the graduate school, but was also, again, more the administration, the secretaries, as well as just the people of the City of New Haven. And so I think my context was growing.

SS: So when did you move to New York?

AB: Well, in '87, I got a Fulbright, and went to Guatemala, where I did my doctoral research. I lived there from '87 to '90. And when I decided to move back to the United States, I had a series of choices. I could go back to New Haven; continue as a graduate student; finish my dissertation; and look for work as an academic. And in part, my experiences during the strike, and also living in Latin America, and obviously, my sense of the world, was growing profoundly. I was very resistant to going back into that ivory tower. And almost again, an idea – I just decided I would move to New York. And that was in December of '89, January of 1990.

And when I came to New York – again, it was a much more difficult transition than I had thought it would be. It was the first time I was out of an academic environment. I was in a pretty difficult city to find work and to find a home. And it was also the first time I had really heard about AIDS. When HIV/AIDS began to affect people in this country and outside, I wasn't aware of it. I was too closed in to my own world. And as AIDS started to hit this city very strongly, I was in Guatemala, and this was pre-Internet, pre-telephone, even, at

least for parts of Central America. And when I came back, I had two friends — one in particular — that were, that was already affected, and infected.

SS: A friend from school?

AB: From school, still living in New Haven; my friend John. And it was in, I suppose, the spring of 1990; a little bit lost, though, myself, and not sure how to — I don't know; gather my strength, gather my sense of self — that I started to go into ACT UP meetings.

SS: And how did you find out about ACT UP?

AB: I had met Laurie Weeks, who was a member of the Marys, and just a terrific human being altogether, through friends of mine.

SS: Laurie Weeks the writer?

AB: Yes.

SS: Was a member of the Marys?

AB: That's how I became a Mary; through Laurie Weeks.

SS: I never knew that. Okay.

AB: Laurie Weeks had just moved to New York. And she was good friends with my friend Faye Hirsch, who I went to graduate school, at Yale. And I met her at dinner, at Faye's house. And she was talking about this group called ACT UP, which I had never heard of. And then, once I got to know Laurie a little bit, she started talking about this affinity group called the Marys. And I was like, the Marys?

Well anyways, I remember walking into Cooper Union, in the Great Hall. And I had just never seen anything like that. The meetings we had at Yale were usually in churches, and there were hundreds of people there, and people spoke extemporaneously, and we were very organized. But ACT UP was like – I couldn't believe the amount of divisions, the layers of it, the complexity of it, how articulate people were. And also the immediacy. There were people at every level of HIV infection at that moment. And I walked in that room, and you could palpably feel the sense of urgency; that there was nothing hypothetical about it. And it was also, to my very academic mind, just a fabulous militia of thinkers, and people willing to take their strength, and what they could think, and then do something with it. It was pragmatism at the highest level. And I was just thrilled by it.

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Also, it was personal to me. I was just beginning to absorb the seriousness of the illness of my friends; and also to become aware of, in the '90s, how discriminated against we were – in part because of our sexuality, and in part because of fear and ignorance around the disease.

And so I was like one of those lost kids, that just found a perfect place, for everything. I had, I was bilingual by that time, in Spanish and English; I had excellent research skills; I was desperately wanting to be part of the world, in a meaningful way. And here it was. And I think from that spring, of 1990, until the spring of 1993, that's all I really did, was ACT UP. I worked, I had jobs, I

found a way to support myself. But it was all to get me to those Monday-night meetings, and all the other meetings I went to, from that point on.

SS: Let's talk about some of those activities. So did you become a Mary?

AB: I became a Mary. I was inducted in Marydom.

SS: Can you tell us who the other Marys were?

AB: Well, I don't know all of them by name, or at least I don't remember all of them. And the Marys – some of them had died, and others joined, and others left. But I could certainly tell you the ones I worked the most with.

Well, Laurie, of course, introduced me to the Marys. Stephen Mishon, who seemed like the Queen Mary. And Joy Episalla, and Jim Baggett; Tim Bailey; and Barbara Hughes, and Jon Greenberg, of course. Those were predominantly the people I worked the most with. And the whole idea of the affinity group; that ACT UP itself was already a counterculture, and then it had to have countercultures within its own counterculture, and also create ways for people to bond and create identities, and then create actions that didn't need to be okayed on the floor, and didn't have the stamp of approval of ACT UP.

I mean, everything about ACT UP was so brilliant organizationally, and it was brilliant because it was organic, and it came out of necessity. And the affinity groups were pure necessity. Because ACT UP always

– when I was part of it, always wanted the freshness of irreverence. And irreverence can't come from consensus. {LAUGHS} And the affinity groups allowed for small groups of like-minded people to do whatever they wanted.

SS: So tell us one of your favorite things that the Marys did.

AB: Well, there were many things we thought of doing, some of which we ended up doing. Probably the two most important things that we did do, and helped to do, was around Day of Desperation in 1991, which was to collaborate with other affinity groups to take over the news stations. Our station was MacNeil/Lehrer. And it was the day before Day of Desperation; I believe January 22nd, 1991. And Joy Episalla had figured out how to — before Photoshop, of course — but figured out how to get our pictures on — so we knew somebody in ACT UP who worked for PBS, and we made fake cards. And we got in. And then we chained ourselves to the MacNeil/Lehrer Report, with handcuffs.

And the only reason we didn't get online – or get on TV — was we hadn't fully appreciated the fact that the MacNeil/Lehrer Report was filmed in two locations. So once we were chained to Robin, they just switched over to Washington. But that footage exists somewhere, because the news crew just kept shooting while we were chanting about money for AIDS and not, and not for the first Iraq war, at the time.

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That was a huge action, in terms of the planning. And the arrests were much more serious than we had anticipated, because when we were arrested, as we anticipated being arrested; we hadn't gotten good enough legal advice, that we were taking over a news station during war. Which is a felony. It's not just trespassing; it's a felony, because news stations are protected during wartime. And so our defense, and our potential arrests, or at least our trials, could have been quite serious. But luckily, the news stations decided to drop it. They thought it was worse for themselves to pursue it than to – bad press for them to pursue it, and so they are the ones who stopped it. Had they chosen to go through with this, it could have been quite serious.

SS: And how do you think Robin MacNeil felt about your being chained to his desk?

AB: He had so much makeup on, it was really hard to tell. What, I was ba-, I, I remember just being fixated on how much makeup he had on. He was as cool as a cucumber. He really was cool.

SS: Did it change their coverage?

AB: There was a moment, there was a glitch, if you go back and look at the footage, where he is trying to explain what's going on, and saying – but he didn't say what was happening. He just said, we're having some technical difficulties in New York, and we're going to have to switch. Because they were interviewing someone at the time; some economist, about the war. And so I

remember the economist being totally amused by the whole thing. And I remember the people who really were supportive were the union people; the videographers and the film crew. They were just – totally great about it.

SS: But I mean, was their AIDS coverage improved after?

AB: Oh no. I don't believe so.

SS: So you don't think it had a long-range –

AB: It's hard to say what has long-range effects. I think that news stations aren't used to being taken over. And I think that over and over again, I think the media learned to take ACT UP seriously — even potentially more seriously than they took AIDS — because we were so savvy, visually, in their realm. And so, like I said, it's hard to say what the long-term effect was.

But I see actions like that as whether you get on the news or you don't, they build confidence, they build experience. We learned a lot. We learned how to protect ourselves for the next action and the next action. So the cumulative knowledge is always meaningful in that way.

SS: I'm very interested in the translation issue inside ACT UP.

Can you tell us a little bit about the history of that, and how that was enacted?

AB: Translation, in terms of –

SS: You said you were bilingual, and –

AB: Well, that – that actually became – well, when I joined ACT UP, or became part of ACT UP, it was just beginning to feel at least, from what I could perceive, some of the needed challenges of thinking about race and gender within ACT UP itself. When you're out there, fighting for your lives, and you're already queer, and you're HIV-positive, you think you're at the margin of marginality. But you're not. There are margins within margins. There are women who are queer and have HIV, who have no representation, in 1991. There are Hispanic people, there are people of color; there are people outside the United States; there are homeless people; which the majority of people of ACT UP were not. And ACT UP was just beginning to realize that it wasn't at the edge of the margin; and in fact, it was, like, kind of the privileged within that margin. And I think it was – these were difficult times in ACT UP, where we constantly had to relook at ourselves, and look at our privilege, and look at our own demographics.

And so language became a huge issue, especially when we wanted to represent different kinds of needs, outside of the epicenter of AIDS as it was reflected in the white male homosexual world. And there were conflicts; it was hard.

And to be specific: in a way, the translation issues came later for me, in 1993 — and we can get to this when you feel appropriate — but I stopped going to ACT UP because I started to work on a pediatric AIDS clinic at Kings

County Hospital in 1993, full time. And so my life entirely shifted, from activism to being right inside of a city hospital, in which my bilingualism was crucial.

And within ACT UP itself, there was a lot of talk about especially making our literature available in different languages, especially Spanish. But there was no organized, systematic attempt at that. I would say it was a conversation on many levels. But it wasn't anything that I was fully involved with until I actually left ACT UP.

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SS: So you never really used Spanish in the ACT UP context.

AB: Not on the floor. There were times when I might translate for people just that I knew, or that had come in; or I might be asked to be a translator at different times. But it was nothing systemic, or part of the organization.

SS: So how did you get involved in pediatrics?

AB: Well, the Marys was one part of my life in ACT UP, and that was kind of my night life; not Monday night. The area where I focused right away was in Treatment and Data; T&D. And the two people I worked most with were Garance Franke-Ruta and Jon Greenberg. And Garance was just a fabulous companion and friend, on every level. We traveled together; we hung out together; we talked about politics and poetry and painting and girlfriends and ACT UP. And I learned a great deal from her about pragmatics and how rigorous we needed to be if we were going to impact on AIDS research and treatment.

And my work with Jon Greenberg was that I was and always have been and continue to be focused on preventative and nontoxic treatments. And Jon was really the heart and center of alternative treatments within T&D, and the Alternative Treatments Committee. And he was also HIV-positive, and ultimately died of AIDS. And so his commitment and knowledge and fierceness were always at the heart of guiding me in what I felt I could do.

I'm a good researcher, and I don't tire of it. So I didn't mind. He would say, oh, look into Hypericin, and see what we can do about this. And I'd be like, okay. And two months later, I'd have a report on hypericin, and we'd come up with a strategy about, what do you do with this information, and how can we translate this into getting this into bodies, and seeing if it is at all useful? It's an extract from St. Johns Wort that potentially would reverse neurologic damage; neuropathy and other neurologic effects of the disease.

SS: So how would you do your research?

AB: In the New York Public Library; talk to specialists; figure out who's worked on this, if anybody. Some of it, nobody had done research on. And so we were really kind of way out there. And at that time, by '92, we were getting invited by the National Institute of Mental Health, by Ellen Stover, to come to their meetings about treatments, frontline treatments as well as alternative treatments, for HIV. And they started to realize that we were their best allies. We'd protest and we'd try to shut them down. But we were ultimately helping

them. And they saw that, very early on. We brought press to them, that they couldn't get otherwise; we brought funding to them; we brought new ideas to them; we challenged them and made them feel uncomfortable. And this is healthy, in a scientific environment.

SS: How did you bring more funding?

AB: Well – any time the National Institute of Mental Health gets on the front page of some Baltimore newspaper, somebody's thinking about it in a way they hadn't been. And it stimulates talk, and it stimulates ideas. And Ellen Stover can say, I just had like 400 people with AIDS at my door, and they want me to study hypericin. And she could use that to get funding.

SS: And why was it mental health? Why were they involved in

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AB: I don't know how much you want to go into this, but in the early years of AIDS epidemiology, or HIV epidemiology, there was a huge fight in the Institutes of Health as to whether AIDS would be defined as a neurologic disease, or a virus. They knew it was a virus. But should the money go to neurology, or should the money go to virology, or should it be split?

The reason for that is that HIV affects the central nervous system much more than anybody wants to talk about; in part because it adds to the stigma of the – I don't know, what people with HIV can and cannot do. If we can say that HIV transmission can be contained by certain behaviors — that you're not going

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to get it by coughing each other — well, that's one thing that we had to work hard at. But if you say HIV affects the central nervous system, then should people with HIV be able to drive cars? Should they be pilots? Should they use chainsaws? These were questions that the advocates within HIV disease were trying to contain; and in a way, tried to push the funding and the idea of AIDS much more into virology, and to steer it away from neurology, because of the implications. And unfortunately, the steering got a little too strong. And the majority of the money was and still is in virology.

The effects of HIV on the central nervous system, however, are tremendous. And some of these effects are not just opportunistic infections. They're more ephemeral, and deserved, early on, better funding and more treatments, especially in children.

The adult central nervous system is totally formed by the time you have HIV infection. But a child exposed to HIV has a developing nervous system, and is much more – detrimentally affected by the virus neurologically. And so –

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SS: So Anna's just explaining why AIDS treatment was under the rubric of mental health.

AB: As I mentioned, Ellen Stover, who was the director of the National Institute of Mental Health, at least during my ACT UP years; she felt that the Institute of Mental Health was not getting the funding it deserved and

needed, especially in pediatrics, in terms of understanding the kind of progression of disease, as well as treatment.

And so she made it clear, very early on, that she appreciated our agitation in this area; that we were protesting for more funds, more research grants, more treatment possibilities, around neurology. And so she invited us to all of her meetings on AIDS — as many as we wanted — and she paid for us to come to them.

And I don't think she was trying to co-opt us, or even influence us. I think she saw us as important – potential parts of the solution. And again, as I mentioned, she could go back to her supervisors at the National Institutes of Health, under which she was part, and quote us as saying that we need this care, that patients are asking for this.

And patient advocacy that ACT UP was able to instill in our members and the people around us was probably one of the most lasting aspects of ACT UP that I can think of; that people felt empowered to get involved in their own treatment not only affected people with AIDS, but I think with all illnesses, potentially. And these were the early years of patient advocacy, getting really involved, and even actively involved in their own care. And she was smart enough, I think, to see how we could partner in this.

SS: Now what did happen to hypericin?

AB: Well, the models for homeopathic and – treatments – are very different from Western medicine. They don't act as silver bullets; they're not meant as such; they're not meant to necessarily cure the disease, but rather to focus on general well-being, and also potentially to benefit a certain aspect of people's daily life. And many of these things are very hard to measure, from a Western scientific point of view.

So the benefits of hypericin were never able to be shown clinically. But that doesn't mean anecdotally, and experientially, it wasn't helpful. And I think that within the AIDS community, there's a lot of apocrypha and hearsay and nontraditional medicine and non-published ideas that are helping people on a day-to-day basis: whether it be just simply the agency of doing something for yourself, and the placebo effect of that; or because the effects really are beneficial, they're just not measurable.

So I would say that there's literature out there, now, for anyone who's interested in hypericin as a treatment of neuropathy or depression or memory loss; not only for people with HIV disease, but people with Alzheimer's or other memory diseases. And because of the Internet now, these kinds of information, this kind of parallel world of medical treatment, has grown exponentially.

So I would say the work Jon and I did was the beginning of something that just continues. But it doesn't register at the level of clinical trial.

SS: What was the role of Alternative Treatments inside ACT UP?

AB: We were like the margin of the margin. It was clear that, again – within ACT UP, there were hierarchies. And Treatment and Data was a heavy-hitting group of people. And there were a lot of superstars in Treatment and Data; very articulate and smart people. And they were pretty much focused on antivirals and antiretrovirals; at the time, AZT, then ddI, and that whole strain of antivirals.

Garance introduces Countdown 18 Months, which was just fabulous, because it focused on the opportunistic infections, and focused on treatments that really were viable. And she was highly respected for that, and had a huge impact, that if one were going to focus on treatment and the well-being of people with AIDS, one needed to look at the bigger picture of HIV infection, but also the opportunistic infections. And by giving the National Institute of Health 18 months to do something, and give ourselves a countdown of 18 months to do something, huge benefits came of that.

Tape II
00:05:00

When it came to alternative treatments, it was a little bit like they had eaten their steak and they'd throw us the bone. Like, go ahead, and work on that, and kinda stay out of our way. And T&D allowed, or invited, us to be like the Alternative Treatment Committee as a subcommittee within T&D. And we acted pretty autonomously.

We were small numbers. And we would get our time slot on the floor, like in the later hours of the night; not prime time. But more and more people would stay and wait for our reports. Because they included things that were acupuncture, acupressure, yoga, meditation, diet, therapie,; hypericin; nontoxic drugs. And –

SS: Garlic. I remember –

AB: Garlic was a big one.

SS: – Jon, standing up; garlic.

AB: And our literature got better; our profile got better; doctors started getting more interested; people that were doing mainstream drugs became interested that these natural or homeopathic or nontoxic or preventative medicines were actually improving their day-to-day life.

And so again: the only things that really worked in ACT UP were the things that worked. They didn't work because they sounded good. They either worked or they didn't. And our profile got stronger, and our integration better, because these things really impacted positively on people's lives. But I have to say, we were definitely on the margins of the margin.

SS: I want to say something very provocative, and I hope you'll forgive me in advance. So you know, Mark Harrington is still alive, and Jon passed away.

AB: Um hm.

SS: Was there any sense that Jon had, as he died, that he had been mistaken in his faith in alternatives?

AB: Well, Jon didn't only take alternative medicines. He was willing to work with Western medicine. He wasn't, in any way, rigid. He just wanted to go at it from multiple angles. So I think his death before Mark's has nothing to do with his treatment profile. It just simply has to do with epidemiology, and we don't know why some people live longer than others, and it doesn't often have anything to do with treatment. Mark just may be a long-time survivor, and he might be that just organically.

So just from a medical point of view, I don't think that there is any way to differentiate how long they lived based on their treatment.

In terms of Jon's own state of mind: I don't think he ever doubted for a moment that what he was doing was the best he could do. He was so – careful and so in tune to himself that I don't think he second-guessed.

SS: Because I went to his funeral, and I still have the memorial glass that the candles were in. And there's a picture of him, and a quote from him, about the positive impact of having AIDS on his consciousness. Can you explain that a little bit? I mean, it's, you're second-hand, but –

AB: Well, I'm kind of getting chills, thinking about it. But, Jon believed in a holistic approach to life. And that didn't just have to do with AIDS or treatment; it had to do with, we're bigger than some, we're part of something

so much bigger than us. And whatever role you can play in those waves that dip and flurry, that's all you can do. And I think he felt he rode those waves pretty well. He was a beautiful being, that could be angry and passionate and sad and in the moment. And I think his ability to stay in the moment, till the moment he died, is all he really wanted. And to be able to do that under the kind of physical and emotional stress of HIV disease is just a beautiful testament. So I really don't think he had any regrets.

SS: Okay.

AB: I believe that.

Tape II
00:10:00

SS: Okay, thank you. So how did you get into pediatrics?

AB: It's all Jon's fault. One of the drugs he was really interested in, but had a very complex pedigree, was something called Peptide T –

SS: Oh yes.

AB: – that was developed by Candace Pert, a rather eccentric pharmacologist, who worked at the National Institute of Health. And she was involved in psychoneuroimmunology; that the body, the nervous system, and the psychology of the being were all wrapped up in one another. But she's hardcore science, but holistic hardcore science. And she was also interested in nontoxic, preventative drugs within the medical models. So she was kind of perfect for us, for Jon and I. And so we were very interested in what she was up to.

And she had developed this drug called Peptide T, named after a peptide. And how it worked – it was so logical; it's just such a complete designer drug. HIV doesn't live in the body by itself; it has to invade a cell, and parasitically then reproduce through that cell. So she just said, well, what does it enter the cell with? It has to have some element of it that it enters the cell with. And usually those are proteins on the outside of the virus.

And so she tried to identify a series of proteins that she felt were potential invaders. And she focused on gp120, which is a protein on the outside of the HIV virus.

So she figured out that she thought that was probably the invader. So what did it invade, what aspect of the cell? And the cell is very protected, but it has vulnerable areas. It has what are called receptors. And the cell is constantly taking in things that it needs, and it's constantly expelling things it doesn't want. So it has permeable portals.

And so she tried to theorize: what was the permeable portal that potentially gp120 entered? And she kind of spun the roulette wheel, and came up with, I think it was CCR5, which is a receptor, one of the receptors on our cells.

So she developed a drug that looked like gp120, and could be a block. It would invade the cell, but it would be just a blank. And it would stop the virus from coming in. It's called a receptor blocker. And it's a brilliant idea, because it's entirely nontoxic; it does no harm.

But, how much of it do you need? How do you take it? These need huge amounts of money and clinical trials. And she was, and remains, a somewhat eccentric scientist. And Ellen Stover was the only one interested in developing a study, because it was nontoxic, and she could get it approved for kids. She couldn't get it approved for adults, because it was too big a long shot. But so few drugs were approved for children that she felt she could – What harm could be done?

And so just, it was just by chance that it became the drug I got very interested in, and it guided me into neurology and it guided me into pediatrics. And as I'd go to these meetings about where these clinical trials could be done, how they might be done, how much money we needed; I met Hermann Mendez, who was, and remains, one of the most active principal investigators of HIV disease in children – at Kings County Hospital, here in Brooklyn. And one day he just walked up to me, and he said, I want you to come work for me. And I was just like, well – I don't even have my Ph.D. yet, in art history; how am I – I mean, I was like, what am I going to do? And he was just like, well – if this study comes to Brooklyn, you could be the project coordinator. And I was like, well, that's great, Hermann, and nice to meet you.

And a year later, the Peptide T trial did not come to fruition. They decided not to do it – in part because the preliminary trials that were done just

showed no ostensible benefit. And I think with Peptide T, it was a terrific idea; there just needed to be more ideas like it, and there wasn't funding for it.

Tape II
00:15:00

But what did come out of our meetings was that we need to figure out, we need to do clinical trials simply on neurodevelopment in children: how is the disease affecting children? So it wasn't a treatment study, it was just a diagnostic study. And also, how do you assess the developing nervous system of children from multiple language groups? Because one of the most important determinants of neurodevelopment is language. But what if you're dealing with doctors and patients who speak diverse languages?

And Kings County Hospital – this is Nico, sorry. [Anna's cat]

SS: Nico?

AB: Nico.

SS: That's your rock and roll cat.

AB: Kings County Hospital, being here in Brooklyn, served a huge Haitian, huge Hispanic, African American, population. And so we got funding to not only test the neurodevelopment of children who were English speakers; but we got funding to do videotaping; and to then analyze the videotapes for micro-changes in movement, as opposed to just focusing on language. And that was the alternative that we chose to – and we felt that we could come up with a diagnostic model that could be used anywhere in the world, if indeed it was successful. And

so it was basically a three-year study of trying to come up with visual markers, as opposed to linguistic markers. {PURRING}

SS: So what you're talking about is this very classic ACT UP phenomena, which is the creation of the citizen-scientist. Right? Because –

AB: I'd never even heard that, but I am sure you're right.

SS: Well, I mean, nothing in your history – never did you say, and then I took a science class.

AB: Oh, no no no.

SS: So how did you, first of all, feel that you could enter into that world? And then, how did you begin the process of getting so sophisticated?

AB: Well, part of it has to do with, some of the things that we were interested in, nobody was studying. So it wasn't like there was this huge body of literature that I felt daunted by, and had to read books and books about. AIDS was still relatively new; the treatments for it, some of them were completely off the boards, in terms of what anybody had ever done. And so you had this feeling, like as long as you could read and think and have your focus on what will actually help people; that you could do this. And that you had to do it, and you needed to do it. Plus, people at very high levels were listening to you, almost immediately. And, people that were affected by the disease wanted to hear what you had to say, and wanted this information to help them make decisions, like tomorrow. And so

you didn't get caught up in insecurities and doubts. You didn't really have time for that.

Plus, I am a university-trained academic. So – can I – I need to put him out.

[Interruption]

SS: – believe me we've seen a lot of cats.

AB: I bet!

SS: So you just used your research skills, basically — your ability to conceptualize and absorb information — and you switched it to science.

AB: Critical thinking is critical thinking. And the more you specialize, the more you can discriminate between what you feel is central and important, and what you feel is not working – or the ability to look at literature and look at outcomes, and be honest about what is the most effective and expedient path, I think has to do with critical thinking. And certainly, the more immersed you are in a particular field, the more agile you become. But we were immersed. I had more experience with people with AIDS than most interns had at that moment. I was– literally, my friends; they were people I was extremely close to. And I could see the effects of things upon them, on a day-to-day basis. So there was nothing – it was all so integrated that it fueled a sense of urgency and confidence; and the decisions you were making were really about life and death,

and we just made them. I don't remember – I think I was more doubtful about my own doctoral work than I was about my AIDS work.

SS: And that you managed to finish your dissertation in the middle of all of this –

AB: Well, no, I didn't, actually. I worked at the hospital, on this pediatric AIDS study, from '93 to '96. And the study came to an end. It had wonderful benefits, in terms of what we were able to just put out there, in terms of children, the effects of HIV disease. Probably the most important finding was that as viral load went down, children's neurologic performance went up; and that neurologic deterioration could be reversed. And that was huge.

And so it was a very gratifying study, in that it integrated me with doctors and patients and people of different cultures and different backgrounds. I also brought in a good deal of holistic medicine to the people in the study. Because I talked to them about it, and also encouraged them in their own cultural treatments, that doctors were not always all that supportive of.

But when the study came to the end, I had to decide whether to – I considered going to medical school; I really did. I also thought of continuing as a project coordinator, which I could have done, if I wanted. And I remember, I was going to Brooklyn — I was living in Manhattan at the time — and I was on the 5 train. And I was going into Brooklyn, and the train got stopped under the East River for an hour. And people were crossing themselves, and – who knew what

was going to happen. And my first thought — which totally surprised me — was, I can't believe I didn't finish my dissertation. {LAUGHTER} And it was at a moment in time when I was deciding what to do. And I chose not to go back to the hospital, and I took a year off. I went on unemployment. I also had some money saved up from, when working at the hospital, I made more money than I needed. And I took all of 1997, and finished my doctorate.

So, in the middle of it all, no, I didn't write my doctorate.

SS: Okay. Now under my Anna Blume prep notes, I have the words “tat inhibitor.” Were you involved in that? No. Okay, that’s an error.

Now this is kind of a peripheral question. But we have footage of you at Kennebunkport.

AB: {LAUGHS}

SS: And I was wondering if you could just tell us the story of the whole Kennebunkport – why that demonstration happened, and –

AB: Well – Kennebunkport was really just one of many actions that ACT UP did. Sometimes we'd be focused on the Church; sometimes we'd be focused on Washington, in terms of legislation; sometimes we'd be focused on deep science. But sometimes we just needed to be focused on the absurdity of our rulers, of the oligarchy of this country, and the Bushes – this was Bush One; it was Papa Bush, not Baby Bush. And we looked at someone like Bush as a

dynasty, and as someone who was hugely powerful, steeped in their own luxury and sense of self and privilege, that excluded people with HIV disease, on every level, in- and outside this country. And so rather than go to them in their professional places of work or worship, we thought we needed to go to his kind of family home, the seat of his privilege, and wake up the people in that neighborhood. Who are their neighbors? Who are these Bushes? And how do they feel about it? Kennebunkport would be in the news as the summer home of the Bushes, and now it was going to be the summer home of the Bushes, invaded by a group of activists, AIDS activists.

And so that was the idea. It was, again, it was a holistic approach; it was, get them everywhere, every way, any way you can; disrupt the sense of arrogance and well-being that people had and used against people with HIV. And get them where they sleep, get them where they rest; get them where they think we can't go, where we don't belong.

Tape II
00:25:00

In Washington, we belong; it's the place you protest. But we don't belong in Kennebunkport. I laugh, because I think of us coming off that bus, in that environment, and just going to the local store to buy potato chips or something. And the looks on people's faces, as to who we were. And we really were Mars Attacks – from another planet.

And it also added — I'm sure people have said this — but ACT UP was also just raucous. We did crazy things. And we enjoyed them. And

Kennebunkport was just a complete, it was a vacation for us. We went to their place of vacation, and we had fun. And it gave great energy. It was also just smart, and we got good press. And again, it said, the message was; there is no place we're not going to come find you.

SS: You said it was like a vacation. I'm wondering if we could talk about sort of the culture of being in ACT UP; going on these long trips with people, and spending so much time with people.

AB: Well – one of the benefits of doing this interview, especially in 2010, was going back and thinking about – I took out my journals. I have seven journals, I have piles of papers, I have photographs, I have – memories that, it was such a moment. Not more than a moment, but a series of years in my life. And nothing like it since or before.

Like, the first year I was in ACT UP, one of the things the Marys did, not just here in New York, having to do with AIDS, is we went to Haiti together. Stephen and I and Laurie and Anne d'Adesky, who was not a Mary, but related — a cousin — we went to Haiti to witness Aristide's, to be UN witnesses for the Aristide inauguration, and also to address AIDS in Haiti, which was a huge, and continues to be, a huge issue.

So the things we did together –

SS: How did you get to be a UN witness?

AB: Because Steve Mishon used to live in Haiti, and Anne d'Adesky had family in Haiti, and they needed people to go and witness the inauguration. I don't know; we were at a Marys meeting, and he said, how many of the Marys want to go, and we'll get plane tickets, and go. And things like that happened all the time. Because we – those of us that, at least that I knew – ACT UP and AIDS awareness was just part of such a larger understanding of political agency, or social consciousness. And so all kinds of things would happen. I mean, people would take you to readings, or to concerts, or have you try foods you'd never tried before, because they supposedly boosted your immune system. I remember smuggling drugs, with Garance, through the People with AIDS Health Group. The PWA Health Group was just a cover for getting drugs into the country that were illegal.

SS: How did you smuggle them?

AB: Through the mail.

SS: You mean you went to Mexico and bought drugs –

AB: Sometimes. I went to Canada, I went to Mexico, or we'd get them sent to us in small amounts. And the FDA actually knew about a lot of it, but didn't shut us down. And People with AIDS Health Group was a completely illegal drug-smuggling group that just gave people with AIDS drugs they couldn't get otherwise.

SS: What were some of the drugs that you smuggled?

AB: A lot of them were approved drugs outside the country, for opportunistic infections. They weren't antivirals, because the United States was always, and continues to be, at the forefront of that. So they were drugs for opportunistic infections, like –

SS: Do you remember any names?

AB: They were antivirals. Garance would know all of them, because she was one of their workers. But I remember one in particular — maybe she told you this story — was for, not PCP pneumonia, but one of the other pneumonias. Because Dapsone pretty much worked for PCP pneumonia. But there were other kinds of pulmonary infections. One was an aviary pulmonary infection — it came from a bird — that people with AIDS – it was called, I think, MAC — were particularly affected by. And we got this one drug from France that was very effective. And people would buy it. And we'd give them dosing information. We'd have to translate what we'd find from French doctors, or
Tape II
00:30:00 Canadian doctors.

And one day, Garance called me up, and she said, you'll never believe this one. I just got a call from the New York City zoo, that the penguins are also getting this particular kind of pneumonia, and they want to buy this antiviral, or this anti-infection drug, from you, that they hear that you're selling to people with AIDS. And they sold it to the public zoo, for the penguins.

So we were drug smugglers; we were, we had to leave the country, come back. There were all kinds of things we were doing that were part of being effective –

SS: Let me ask you this. Very often, when we interview people, they'll say: And then we all got airplane tickets.

AB: {LAUGHS}

SS: Then we all went there, and the hotel room, blah blah. It's like there was a lot of money available; there was a lot of access, there was a lot of going here and going there. Where did all that come from? Or how did you experience this?

AB: – it's a good idea, because I was so broke. I, ecch, there were weeks where you were hoping there'd be a meeting, because there'd be food there, or something.

All of the trips to Washington were paid for by Washington. Or at least the ones I was part of; the National Institute of Health. When we took big buses, I don't know who paid for those. You just showed up; nobody ever asked you for 12 dollars for the bus to Washington. The bus just showed up, and I don't know who paid for those things.

When we went to Haiti, Steve said, tickets to Haiti weren't all that expensive. He said get the ticket, and we'll take care of you once you get there.

So I don't remember ever really stressing about doing anything. Like when we went to Kennebunkport, nobody paid for the bus; at least not that I know of.

There were people in ACT UP who did fund-raising, that were quiet. Like Bob Gober. He was somebody who was very successful himself as an artist, but also had connections. And he's a very quiet guy. But he could get money for things. And you'd never hear about it. He wouldn't announce it on the floor of ACT UP. And I think there were people you maybe don't know about, or that want to remain somewhat anonymous, that really were the money behind things.

SS: Were you ever aware of, or having thoughts about, how much access ACT UP had?

AB: Well, I think, as I mentioned, the margin of the margin question; there was a lot of grumbling about how privileged ACT UP was; and about how it needed to broaden its awareness of who was affected by this disease, and who was going to be able to afford these treatments, and who were clinical trials being geared towards. So there was that internal tension and debate, about what access we had and how we were using it – if that's what you mean.

In terms of how powerful we were, and how effective we were: I found it extraordinary. At the moment, I could, I knew that this was something very unusual, and that it would last for a particular period of time, but that it

would also, it couldn't sustain itself beyond a certain moment. So I was amazed and delighted at how expansive and how effective it was. Not just for the people who were living with the disease, but for the culture in general, right? I think ACT UP has given many gifts to the world, that we're still feeling; I certainly am still feeling.

SS: Okay, I want to go into a whole new thing. I want to ask you to put on your art-historian hat.

AB: Okay.

SS: So ACT UP was filled with artists. And there was collaborative work, there were gallery artists, there were street artists. Were you looking at all of that, conceptualizing it, talking to people? Or was that something that was a separate part of your life at that time?

AB: I wasn't that involved in it, at least not from that point of view. I think I was highly sensitive to how visual ACT UP was. And I was always part of making decisions about what we would look like, how we would dress, how we would appear; what our strategies would be; how we would affect the press. I think we were strategists, and visual strategists, and performance strategists. And my interest in aesthetics, and my sensitivity to how important visual experience is, I think was hugely important to my work in ACT UP, and also why ACT UP was so important to me; was that it communicated on the level that I existed, and that was just organically important to me.

So I guess I didn't see it as an outside element, or an epiphenomena. It was everywhere.

ACT UP was also about a bunch of people, really sexy, beautiful people, talking to each other, and attracting each other, and exciting each other. And we were all dressing for each other. Those ACT UP meetings, you'd get dressed up for, just because you didn't know who you'd meet. And it was part of the confidence that people in ACT UP had, and part of the sense of trying to create a culture where we looked at each other and recognized each other.

So I guess the aesthetic and visual of it was just very – integral for me. Almost all my friends in ACT UP were artists, were visual artists, painters, sculptors, photographers. And I think that just made it – why we agreed about everything, it seemed, heh. Or at least we got on so well. But I never really stood back from it.

SS: But later, when you went back to do your dissertation, did you find – or now that you're a professor – that the ways you think about art and art-making were affected by your experience in ACT UP?

AB: I think it's kind of a continuum. My work in graduate school started to become more class-oriented and more social – I began to bring more social consciousness into art production, and the meaning of art and the making of art, in graduate school. And living in Latin America certainly increased that.

That art is not just something that's in a museum, or in a published book. But it's about a way of life, and about how you present yourself, and how you speak.

So I think ACT UP just exponentially grew that awareness in me. I don't think it created that awareness, but it certainly expanded it.

SS: Do you think that ACT UP artists made a substantial contribution to American art practice?

AB: I think ACT UP and AIDS and art are deeply related to one another, and how to tease out that relationship is maybe more than I'm up for.

SS: Okay.

AB: I think one thing I could say was that – what was happening in the '80s, in terms of the art world, independent of ACT UP or AIDS, had to do with big money coming into art. And the change in the tax laws that allowed and encouraged people to use art as collateral for other investments, changed the nature of who started collecting art in the '80s. And so art started to become part of people's economic profiles; people who had never been interested in art. They weren't the Medicis of the 1980s; they were simply savvy people that saw art as a good diversification of a portfolio. And how were people like that going to respond to socially conscious, in-your-face, performance, video, print artists? And surprisingly enough, they embraced that world, as edge; not as meaningful, but as capitalistic edge.

And so I think that that, happening in the art world, and the kind of growing expressiveness and politicization of certain artists around HIV disease – there was just an interesting meeting of the two. And I think socially conscious artists in the '80s and '90s were in many ways extremely well supported, in ways that were very unpredictable.

SS: Do you think that they understood the contradiction that you just –

AB: Who's they?

SS: The artists who benefitted from the commodification of the edge?

Tape II
00:40:00

AB: I think, to a certain extent, yes; at least the ones that I knew. I think they kind of didn't fall for it. Some did, I think. But I think some just kept riding that potential, and stayed very true to their work.

But on a deeper level and not so market-related. I think that ACT UP always understood itself as acting up, and that it was always acting, and performative, and saw itself as meaningful in its ability to express and externalize the id of HIV expression – or it knew it needed to be out of control if it was going to exist at all. There was GMHC, there were so many other things that were in control, and that had accountability; and that ACT UP always had to perform, and always had to perform beyond itself. And so I think there was always an aesthetic to it, of that.

Tape III
00:00:00

SS: Okay. Let's change tapes.

JAMES WENTZY: Rolling.

SS: Okay. So Anna promised us a Tony Shafrazi story.

AB: Well, in about 1995, I think it was, there was talk about an AIDS treatment center, or a Housing Works center, in SoHo. And I remember a group of SoHo residents — that included Rosalind Krauss, the academic, as well as Tony Shafrazi, who was of course a gallery owner there — wrote letters to the mayor and the city, protesting against an AIDS treatment center in Soho, saying that it would bring drug users and derelicts into the community.

And these were the letters: I have Rosalind Krauss's letter somewhere. It's just appalling, when you think of her kind of socially conscious writing in *October* magazine. And we got a hold of these letters because somebody in ACT UP, of course, worked for the mayor's office. And we had a pile of them, and we started to focus on these people, trying to expose them: to say how completely hypocritical of them, to either, one, profess a certain kind of political point of view, but when it came to their own backyard, not wanting people with AIDS anywhere near them; and how ironic that Tony Shafrazi, part of his fortunes being made on the Keith Haring estate, who of course died of AIDS; and how could he possibly write against an AIDS treatment center in Soho itself? The whole success of SoHo had to do with so many people with HIV disease that it just seemed sad and ironic, and these people needed to be exposed.

So we did write letters to Rosalind Krauss, to her supervisors – not that she minded it, Columbia University, but we also wrote to her students, and they seemed to mind. And we also tried to expose Tony. And he fought back. I mean, he basically said, it's one thing to create, in this historic environment, a place to show art. It's another thing to treat disease. And these things need to be understood in different ways.

And so I remember that morning. I was so frustrated. And I was walking my friend's dog, and I put a whole, huge wad of dogshit into his mail slot –

SS: {LAUGHS}

AB: – just because, I don't know, I just needed to do that, so that his idea of contamination would be brought into question.

And so about a day or two later, I was talking to him on the phone, asking him to rescind his letter. And he said, I am not rescinding my letter. In fact, I am, people are aggressing against me. I just had dogshit put into my gallery.

And I had to just sit there, on the phone, and just say, well; you know; shit breeds shit. {LAUGHTER}

SS: That's kind of like what you said to the president of Yale.

AB: Yeah. Well, what comes around goes around.

SS: Talking back to patriarchs every once in a while can't hurt.

AB: But anyways –

SS: How did Rosalind Krauss respond?

AB: Rosalind was deeply embarrassed. She didn't rescind her letter. But from what I understand, students did confront her in class. And the letter was there. It was signed. She didn't say it was a forgery.

SS: It's so interesting that part of ACT UP's strategy is around the idea of consequences for people's actions. We were constantly creating consequences for things that people felt that they could get away with. And that was a sort of new dimension in everyone's life, because usually these people just act without any kind of accountability.

AB: I think that that was absolutely one of our strategies, and our irreverence was just hugely important. It helped us be bold, and it also just disrupted people's sense of what they thought they could get away with. There were so many acts of irreverence that we used to do, that were about emboldening us; but also letting people know that we were a bunch of tricksters, too, and that they couldn't predict us, they couldn't contain us.

I remember being with Derek Link out in New Jersey, in an action where we chained ourselves to some pharmaceutical company that was upping the

price of their antiviral. And they were giving us a whole runaround as to why the price had to go up.

And at one point, Derek unchained himself, to go use the bathroom. And he walked through the common room, and a fax came in at that moment. And he just took the fax to the bathroom. And then he came back, and chained himself; and then started arguing with the CEO about how he was lying, based on the fax that he had just taken out of the fax machine. And the CEO was just standing there, like – he couldn't refute it, it was right there.

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It was acts like that that were constant, and that we encouraged each other towards. And I think it helped break through environments that had previously been, or believed to be, impervious.

SS: Now this question about meds pricing. That was a huge thing in ACT UP, and we did many, many, many actions, small and large, around getting prices reduced. What happened to members of ACT UP who could not afford meds?

AB: Well, when it came to alternative treatments, that I was more involved in, they were less expensive. And affinity groups sometimes would kick in, and buy things for people. Sometimes we would get, we knew many of the PI's, the principal investigators, of treatments. And you could get what was called compassionate use access. And we learned about these strategies – either getting drugs as gifts, or getting compassionate use for experimental drugs.

If any drug was under trial, even if it was already released; if it was under trial at all, drug companies are required by law to give compassionate use access to people who can't afford the drug, and who also do not qualify for the clinical trial, or do not want to be in the clinical trial.

So there were ways that we found to get people drugs, at least within the small, or relatively small, community of ACT UP; small compared to the rest of the world.

So we were very active in finding ways to make sure that people had treatment if they wanted it.

SS: Did you have sick people coming up to you, and asking you for advice about treatment?

AB: Oh, all the time.

SS: What would you do?

AB: Especially alternative treatments.

SS: Yeah, what would you do in those cases?

AB: Well, the first thing you do is just be incredibly humble. You try not to pontificate with anybody. You just tell them what you know, and what you've seen; and also, give them numbers of people who did these things. I might say, oh, we've done this research on hypericin. We don't think it's going to hurt you; this may be how it's going to help you. And here's this person who's been taking it for six months, and had positive results. Call them, and talk to them.

You'd try to give anybody everything you had. But not just say, oh yeah, try that, and get back to me. You learned to be a good comrade, in a way. You told them what you knew, and you'd be really respectful of their choices.

People that I loved were taking drugs that I thought were killing them.

SS: Like what?

AB: Like AZT. Especially in the high doses that it was given early on. I think that it actually increased opportunistic infections, it weakened the immune system; and they were just bombarding people with it. And I know quite a few people I think died prematurely or died at all because of AZT treatment.

SS: So were you part of the debate inside ACT UP about whether or not it should take a position on AZT?

AB: I would never take a position for or against a drug, personally. I would take a position on information about a drug. I just think that – unless I knew something malicious about a drug. If I didn't agree with its philosophy, that's my –. And I'm glad to talk with anybody about it. But I wouldn't advocate for or against a drug.

SS: Okay.

AB: If I thought there was bad science, or things that were being kept from people, I'd want that to be brought forward. But I wouldn't speak out against a drug.

I think, especially for those of us who were not HIV-infected, I think that you had to learn how to talk and think about these things. You couldn't just be knee-jerk about it, because –

SS: Right.

AB: – other people were making decisions and were vulnerable and scared, and you had to find ways to talk about it that made them feel safe, that they could do whatever they chose to do. And that was hard, at times. My dearest friend, John, died, I think, many years before he might have, because of AZT treatment. And I tried to find ways to talk to him about it. But I couldn't – I had to be very gentle, at the same time. It's his decision.

SS: It's interesting, because given how much he believed in nontoxic treatment –

AB: Not Jon Greenberg –

SS: Oh –

AB: It was a man by the name of John D'Amico, who I knew from graduate school.

SS: Oh, the guy from New Haven.

AB: Uh huh.

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SS: Yeah yeah yeah.

AB: It wasn't Jon Greenberg, no.

SS: Okay. So now I want to ask you about the split in ACT UP. Can you let us into your perspective, or your experience, of that time?

AB: Which split are you referring to?

SS: Well, I don't know. Which one are you thinking of?

AB: Well – well, there were many – there were many arguments in ACT UP –

SS: Right.

AB: – especially around women with AIDS and the issues around visibility of women, and women's issues, and women's voices in ACT UP. But I was already working at the hospital by the time ACT UP started to split, in the big-split terms. In '93 — that is, the spring of '93 — my good friend John died. In the summer of '93, Jon Greenberg died, and Tim Bailey died, and those were the political funerals.

And I was already working at the hospital at the time, in pediatrics. And when I took the job at Kings County, it was full-time, it was overwhelming, and it was all of me. And though I knew what was happening with the Marys and ACT UP, I was not directly involved any longer. Which was a split within me.

That was very personal, and had its own sadness to it. And my feeling not sure if I was betraying ACT UP, or if I was just doing what I felt was

the most important thing for me to be doing at this moment. And part of the draw to Kings County was that it actually was, in some ways, more true to at least the particular study I was being involved in, it was more socially diverse and open. And it felt like a really good place to go with what I had. Whereas ACT UP had its frustrations for me by '93.

SS: What were they?

AB: Issues around looking at AIDS from a more global perspective; looking at AIDS from a more global perspective within the city; talking more about race and gender, in terms of – My friends didn't go without drugs, but people in the city went without drugs and treatment and information. And ACT UP, there were organizations that spun out of ACT UP, like Housing Works or GMHC, that was its own organization, that were dealing more with social issues. But ACT UP was not, at least as effectively as some of us wished.

SS: Were you involved in debate about – were there specific things that came up on the floor that –

AB: I know these were being talked about, and I heard more about them after I stopped going. So I can't say I'm the best person to –

SS: But just in terms of your own personal frustrations, were there concrete things that were going on that you felt were – or not going on, that –

AB: Well, I think that male sexuality and male vulnerability within HIV infection was clearly talked about all the time. And being better and better understood. And supported. Women's sexuality, women's vulnerability, women's relation to HIV, was something that was constantly on the periphery, and sometimes hostilely kept there. There were battles on the floor, where you'd see like the Heavy Metal T&D guys, over on the right, and then on the left, there were more and more women that were gathering, and stronger, vocal women started to actually be in different parts of Cooper Union, in the Great Hall, where you actually felt that there were parties that were forming, and divisions that were forming. And sometimes there was total agreement. But when women's issues were raised, and women's health issues, and women's sexuality and women's visibility, there wasn't the same urgency or collective support. And that was, people felt that, and I certainly could see it. And I sat in the middle of the room. I remember exactly where I sat. And so I could look –

And I didn't actually feel entirely embraced by either camp. I felt like I kind of was in between.

And there was this one historic moment. I don't know if I remember it correctly. But I remember, women started feeling so frustrated that their issues weren't being spoken of on the floor of ACT UP, but also not in the clinical trials and not in our meetings with the NIH, the National Institute of Health; was that one idea came up, that we weren't going to mention women for

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six months. We were just never going to mention anything about women for six months, as a way to protest the fact that women were almost never talked about anyways. And so any time anybody mentioned something about women, we were going to say, no, you can't talk about that.

And I remember – this was a strategy, as a way, it was a political strategy that was being discussed on the floor. And I remember somebody — and I don't exactly remember who — from the right side of the room, a man, stood up, and says, I don't have six months.

Like – right – I am, I may not live six months. So what are you talking about?

And that, there was a silence in the room. And there was this moment of self-reflection, I think, at least on my part. Like – there are different experiences in this room, from different backgrounds and different genders and different ideas. And this is a moment of conflict, and we need to keep working on this. It didn't seem like a bad moment; it just seemed like a crescendo of, how do we put our heads together?

And if the guy that stood up and said, I don't have six months – what I was hoping is, he'd say, okay, try this. Because the women you're talking about, a lot of them don't have six months, either. But that conversation, we weren't ready for it yet. It got polarized instead.

SS: But also because the change in the CDC definition took four years.

AB: Um hm.

SS: So if we were never allowed to do anything that was going to take longer than six months, a lot of things never would have been accomplished. There's always – everybody handles disease and death differently. And there were always people who thought about other people through the time of their death, and there were people who never thought about anyone, when they were fine –

AB: Um hm.

SS: – or when they were sick. It's even more complicated now than it was at that moment, in some sense.

AB: In what way?

SS: Because I remember those kind of moments. And then you'd think: oh, you're right. And now I realize, no, he wasn't right. Because now I see that the long haul also has this other kind of value.

AB: Well, whether he was right or he was wrong, what happened in the room at that moment was an impasse. And I think that that, to me, indicated that's where we are; we're at an impasse, and we don't know how to talk to each other very well. And that was late in my ACT UP years. But it was also – separate from the affinity groups, there were other groups that were

forming, like fierce pussy, or WHAM, or WAC, that weren't necessarily focused on AIDS, but on sexuality and visibility. And some of these groups grew directly out of ACT UP, and grew out of a frustration or a limitation within ACT UP.

So it wasn't like women felt frustrated and did nothing. There was a frustration, and the predominant focus of ACT UP was on white men – white gay men. But we were constantly looking for outs. There was no one that was going to whine. It wasn't a group of whining people.

SS: No.

AB: So if you felt frustrated about something, the next thing you knew, you were wheatpasting someone's pussy out there, on a billboard. I remember Zoe Leonard had decided, with a group, to do a series of women's vaginas with "Read My Lips: Women Get AIDS Too." And she just asked me, will you lay down on my kitchen table, and I'll take a picture of you. And I was just like, okay. And the next think you know, I was seeing – Is that my? –

SS: You know, it's so funny. When we interviewed her, I asked her who the model was, and she wouldn't say.

AB: Well there's more than one.

SS: — there's more than one. Okay.

AB: Well, because she didn't just do that project. She did that project. But after that project, she was invited to show work at Documenta, in Europe, which was a large international art installation. And it was in this

museum. And there was a room of 19th-century, or 18th-century paintings that were slightly lascivious, of women, in this kind of gorgeous Baroque room. And she asked them for that room, to install a group of photographs. And what she did was she left the kind of pastel, boudoir-like room intact; and left some of the paintings there; and interspersed crotch shots, or mug shots, of women's vaginas. And that included several of us.

SS: Um hm.

AB: And that fine-art installation completely grew out of the political poster that she had done. I mean, she had done the political poster first, and then the installation at Documenta came as a kind of fine-arts idea of doing an intervention – not about AIDS particularly, but about female sexuality; and what did it mean to have a kind of touchy-feely, kind of strangely erotic image, of a woman in pastels, next to a complete mug shot of a woman's vagina? And it was a terrific installation. But there is a moment where you can really see her making choices based on what she's learning in the street, and what she's doing at a very high level of fine arts.

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SS: All right, thank you. Is there anything important that you feel that we haven't covered?

AB: For those of us — and I think it's only to repeat — for those of us who were directly involved in ACT UP, and lived: I think it definitely lives in us, on a everyday moment. But I do see it as a remarkable model of what can

be done, in the best of ways, when people draw on their strengths and their different strengths and do things they don't know they can do. And I really believe an oral project like this and its collective vision is something I hope will inform others to do outrageous things.

SS: That's what we all hope. I just have one last question, which is: Looking back — and this we've asked everybody — what do you feel is ACT UP's greatest achievement, and what was its biggest disappointment?

AB: Its greatest achievement was in how it drew on the compassion and strength of a huge group of people, for the betterment of themselves and others, at a time of tremendous crisis – physical crisis, social crisis, discrimination, death. And the collaboration and the working together to address that human catastrophe was its greatest, I think has to be its greatest contribution.

It's kind of like – political activism, like flowers; they can't last. So that it didn't last beyond a certain point, I don't see as a disappointment. It's just the biology of activism. It can't last longer than a certain amount of time. And ACT UP lasted a lot longer than most.

SS: Okay, thank you. Thank you. I hope you feel like you had your say.

Okay, good. AB: Ahhh –